CONSULTATION QUESTIONS

Are you responding *primarily* as a data custodian, data user or data subject? *(We recognise all people are data subjects and many organisations act as data guardians and data users, but <u>please tick only one box</u>)*

Data Custodian ☐

Data User (e.g. researcher) X
☐

Data Subject (e.g. member of the public or group representing citizens) ☐

1. Are there any benefits of data linkage for statistical and research purposes that are not sufficiently described here?

Yes, there are further benefits ☐   No, the benefits are described fully X
☐

If you ticked 'yes', please describe the further benefits of data linkage for statistical and research purposes.

Comments

2. Are there challenges or barriers preventing more effective and efficient data linkages for statistical and research purposes taking place that are not sufficiently described here?

Yes, there are further challenges ☐   x No, the challenges have been identified ☐

If you ticked 'yes', please describe the challenges or barriers.

Comments

3. Are the guiding principles sufficient and appropriate? Please explain your answer fully and make suggestions for improvement.

Yes, they are sufficient and appropriate ☐   No, they are not ☐x

Please explain your answer fully and make suggestions for improvement.

Comments
- 20-22. I have concerns about the appropriateness of these items. Requiring 'explicit consent' and 'adequately' informing subjects of data usage, would appear to require identification of these subjects to the

research team or, more likely, the data custodians, in order to contact them to ask for this consent/give this information. The Australian case demonstrated that data was actually *more* anonymous because no-one knew the names or personal details of participants, in contrast to your conventional research study. By necessitating contact, these principles remove this additional major benefit of data linkage. It would seem unlikely that the broad NHS consent to share data would be enough to cover this 'explicit' consent and adequate information about storage and use of data. I would also suggest that 'opt-in' processes on a study by study basis would result in very low uptake, which is arguably unethical in itself, resulting in a heavily biased or simply unusable sample.

- 33. I understand why distinctions need to be maintained between each of the functions, however I am concerned that Linkers are separated from data custodians as, at present ISD and education services often provide excellent linkage services for us, which I think would be prohibited under this principle. I think there may also be a conflict of interest in ISD being part of the National Data Linkage Centre if this principle was maintained, which would be unfortunate.
- Although the challenges comment that there is no single identifier on all databases (or even the key databases) this is not addressed in the guiding principles. In Glasgow, talks are already taking place about making CHI available on the SEEMIS system in order to make linkage quicker and easier. It would be good to see a principle around this.

4a. Are the objectives set out for a Privacy Advisory Service in Section 3c the right ones?

Yes, the objectives are right x ☐   No, they are not ☐

Please explain your answer fully and make suggestions for improvement.

Comments

4b. Do you wish to be consulted on firmer proposals for a Privacy Advisory service as and when they are developed?

Yes X☐   No ☐

5a. Are the functions that will be led by the National Data Linkage Centre set out in section 3d the right ones?

Yes, they are the right functions X☐   No, they are not ☐

Please explain your answer fully and make suggestions for improvement.

I think that where data linkage is difficult at present, this centre with these functions may help to facilitate future linkage. My concern is that where linkage is currently happening appropriately, securely and successfully, as it is between the University of Glasgow, Glasgow City Education Services, NHS GGC and ISD, for example, any requirement to go through this centre may result in long delays and may actually hinder future linkage.

I would also be keen to see the Scottish Longitudinal Studies Centre as part of this collaboration as they have established considerable expertise in this area.

5b. Do you wish to be consulted on firmer proposals for a National Data Linkage Centre as and when they are developed?

Yes X☐   No ☐